

## Evaluation of perceived family burden, care burden and quality of life of caregivers during the pandemic period

Evaluation of perceived family burden, care burden and quality of life of caregivers of patients

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### Abstract

**Aim:** In this study, we aimed to evaluate the perceived family burden, caregiving burden and the quality of life of people who have to spend most of their time at home with their patients during the pandemic period and who provide home care for patients diagnosed with psychotic disorder.

**Material and Methods:** The study included caregivers of 91 patients with a diagnosis of psychotic who admitted to the psychiatry outpatient clinic during the pandemic period and met the study criteria. All participants were applied the World Health Organization Quality of Life Form (WHOQOL-BREF-TR), Perceived family burden scale (PFBS), and the Zarit Caregiver Burden Scale (ZBS).

**Results:** Participants' mean PFBS score was  $65.6 \pm 19.1$  and their ZBS mean score was  $56.2 \pm 14.8$ . A positive correlation was found between PFBS score and ZBS score ( $p=0,00$ ,  $r=0,763$ ). Also, a significant negative correlation was found between PFBS score and WHOQOL-BREF-TR scale sub-scales and the ZBS score and the WHOQOL-BREF-TR scale sub-scales.

**Discussion:** The pandemic period negatively affected caregivers of patients diagnosed with psychosis.

### Keywords

COVID-19; Psychosis; Caregiving burden; Perceived burden; Quality of life

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## Introduction

Coronaviruses (CoV) are a family of viruses that can previously cause serious diseases such as MERS-CoV and SARS-CoV. COVID-19 infection, which has different characteristics from coronaviruses that cause MERS and SARS, causes asymptomatic cases as well as symptoms of fever, cough, shortness of breath, pneumonia and subsequent severe respiratory failure or even death. The World Health Organization (WHO) declared it a pandemic in 2020 due to its rapid spread and fatal consequences [1].

During the pandemic period, individuals experience not only physical but also psychosocial problems. The feeling of loneliness at home, separation from loved ones, reduced freedom, and uncertainty about the course of the illness can have negative effects on the mental structure. This can cause anger problems, related behavioral problems, and communication difficulties [2]. Depression, anxiety disorder, panic disorder, other mood disorders, even psychotic disorders may occur as individuals or their immediate surroundings have COVID-19 disease and adverse conditions intensify during the course of the disease. Unfortunately, the prolongation of this process may cause psychiatric symptoms to become chronic and increase in suicidal thoughts in connection with the increase in hopelessness [2].

The caregiver has important duties in the form of routine health care, personal care, transportation, doing small housework, money management and sharing the same house. The difficulties experienced by family members who take care of a person with a serious psychiatric illness are generally defined as "caregiver burden". It is known that caregivers of individuals diagnosed with schizophrenia and other psychotic disorders are quite tired. The course of the disease, the frequency of exacerbation episodes, as well as social support, the degree of stigmatization of the society, the quality and availability of mental health services also affect the level of difficulty experienced by the caregiver [3, 4].

Family members experience a perception of the burden against the disability that develops in the patient [5]. The perceived family burden is the negative impact of a person with psychiatric illness on the family. It is stated that both the negative results that develop against family routines and the emotional distress experienced by the caregiver [6]. It is known that the perceived burden on caregivers can affect the level of well-being, care satisfaction, relationships with other individuals, and perceived disease severity [7].

It was known that caregivers of psychosis patients experienced sadness, fatigue, emotional exhaustion, sleep disturbance, guilt, social isolation and financial difficulties before the pandemic [8]. It is estimated that the current problems of caregivers of patients with psychosis are increasing during the pandemic due to the prolongation of time spent at home with psychiatric patients due to social isolation, difficulties in accessing health services and inability to actively use community mental health centers [9]. In the studies we conducted, we could not find studies on the perceived family burden, caregiving burden, and quality of life of caregivers of patients with chronic psychosis in the COVID-19 pandemic. We think that this study will contribute to the literature.

## Material and Methods

People who were caring for a patient diagnosed with a psychotic disorder (schizophrenia, delusional disorder, schizoaffective disorder) who was admitted to the psychiatry outpatient clinic of the Faculty of Medicine, XXXX, XXXX during the COVID-19 pandemic were included in this study after obtaining approval from the local ethics committee. This study followed the principles of the Helsinki Declaration. In this way, 91 participants aged 18-65 who were literate and signed written informed consent form were included. Individuals with physical and mental disorders that might hinder responding to questionnaires and scales were excluded from the study. All participants were applied the sociodemographic data form, the World Health Organization Quality of Life Form (WHOQOL-BREF-TR), the Perceived family burden scale, the Zarit Caregiver Burden Scale.

Approvals of the Local Ethics Committee of Firat University and the Scientific Research Platform of the Ministry of Health, Republic of Turkey were obtained for the research.

### *Sociodemographic and Clinical Data Form*

The semi-structured form includes socio-demographic information such as age, gender, marital status, education, occupation, economic status, family structure and clinical data.

### *Perceived family burden scale*

It was developed by Levene et al. to evaluate family burden in families with members diagnosed with schizophrenia. The scale is filled in by the patient's relatives. It consists of 24 items in total, and its Turkish validity and reliability study has been conducted [10, 11].

### *World Health Organization Quality of Life Form*

This form is an assessment tool developed by the World Health Organization (WHO) for subjective assessment of the quality of life in various countries. Psychological, physical, social, environmental and national context scores are calculated for all items, except the first two general items. Higher scores lead to higher levels of quality of life [12]. The Turkish validity and reliability study of the scale was conducted [13].

### *Zarit Caregiver Burden Scale*

The scale, which is used to evaluate the difficulties experienced by caregivers of individuals in need of care was prepared by Zarit et al. It is a 5-point Likert type scale. The scale score range is between 0-56, and the higher the scale score, the higher the problem experienced, and the Turkish validity and reliability study of the scale was conducted [14, 15].

### *Statistical analysis*

The analyzes were evaluated in the SPSS (Statistical Package for Social Sciences; SPSS Inc., Chicago, IL) 22 package program. The compliance of continuous variables to normal distribution was evaluated with the Kolmogorov-Smirnov Test. Independent Samples t- test was used for comparison of variables that comply with normal distribution, One-Way ANOVA test was used when more than two groups were compared, the Mann-Whitney U Test was used for comparison of variables that do not comply with normal distribution, and the Kruskal-Wallis test was used when more than two groups were compared. In examining the relationship between continuous variables, the Pearson correlation test was used for those who comply with the normal distribution, and the Spearman correlation test for

those who did not comply with the normal distribution. The statistical significance level was accepted as  $p < 0.05$  in the analysis.

**Results**

Ninety-one relatives of the patients were included in the study; 50.5% of the participants were women and the average age was  $44.9 \pm 9.9$  (min=23, max=67) years.

It was observed that the patients followed up were mostly diagnosed with schizophrenia (74.7%), and the highest degree was parents (27.5%) and siblings (25.3%). It was determined that 65.9% of the patients admitted 1-3 times during the pandemic period and 34.1% admitted 4 or more times.

ZBS scores of women were significantly higher than men's scores ( $p=0.043$ ), and single participants' PFBS scores were higher than married participants' scores ( $p=0.008$ ). A significant difference was observed in terms of PFBS scores between the state of being close to the patient ( $p=0.007$ ). During the

pandemic period, the PFBS score of those who admitted to psychiatry outpatient clinic 4 or more times was significantly higher than the score of those who applied 1-3 times ( $p=0.049$ ). During the pandemic period, a significant difference was found between inpatient admissions to psychiatry in terms of PFBS and ZBS scores ( $p < 0.001$ ). A significant difference was found between using psychiatric drugs in terms of the ZBS score ( $p=0.024$ ). It was seen that this difference was related only to the difference between oral and injection treatment (Table 1).

The scores of the participants' quality of life sub-scales were reviewed. A significant difference was observed between economic status in terms of the environmental sub-dimension ( $p=0.034$ ). The physical health sub-scale score of those who admitted to a psychiatry outpatient clinic 1-3 times during the pandemic was significantly higher than the score of those who admitted 4 times or more ( $p=0.039$ ). During the pandemic period, a significant difference was found between inpatient admissions to psychiatry in terms of WHOQOL-BREF-TR scale

**Table 1.** Comparison of PFBS and ZCBS scores according to various parameters

|  |                            | Total   | PFBS total score        |        | ZCBS                    |        |
|--|----------------------------|---------|-------------------------|--------|-------------------------|--------|
|  |                            | n/%     | Mean±SD                 | p      | Mean±SD                 | p      |
| Gender   | Female                     | 46/50,5 | 67,5±20,3               | 0,352  | 59,3±13,9               | 0,043  |
|  | Male                       | 45/49,5 | 63,7±17,9               |        | 53,1±15,2               |        |
| Marital status   | Single                     | 12/13,2 | 79,2±22,6               | 0,008  | 62,3±11,2               | 0,126  |
|  | Married                    | 79/86,8 | 63,6±17,8               |        | 55,3±15,1               |        |
| Educational status   | Secondary school and below | 41/45,1 | 68,5±20,4               | 0,197  | 57,2±14,5               | 0,586  |
|  | High school and above      | 50/54,9 | 63,3±17,8               |        | 55,5±15,1               |        |
| Residence  | District                   | 24/26,4 | 59,0±16,2               | 0,047  | 51,5±15,5               | 0,07   |
|  | City                       | 67/73,6 | 68,0±19,6               |        | 57,9±14,3               |        |
| Income   | Low                        | 13/14,3 | 63,5±18,9               | 0,881  | 55,8±16,9               | 0,924  |
|  | Intermediate               | 67/73,6 | 65,7±18,0               |        | 56,6±13,7               |        |
|  | High                       | 11/12,1 | 67,5±26,4               |        | 54,7±19,7               |        |
| Profession   | Student                    | 3/3,3   | 63,0±20,7               | 0,221  | 61,3±13,1               | 0,215  |
|  | Public officer             | 26/28,6 | 67,9±20,2               |        | 55,9±13,6               |        |
|  | Worker                     | 26/28,6 | 65,3±16,7               |        | 58,2±15,8               |        |
|  | Private sector             | 15/16,5 | 55,9±18,1               |        | 48,4±15,5               |        |
|  | Unemployed                 | 21/23,1 | 70,5±20,1               |        | 59,0±13,9               |        |
| Disease diagnosis  | Schizophrenia              | 68/74,7 | 64,8±18,7               | 0,755  | 57,1±14,7               | 0,472  |
|  | Delusional disorder        | 11/12,1 | 69,4±18,3               |        | 51,2±14,4               |        |
|  | Schizoaffective disorder   | 12/13,2 | 66,7±23,1               |        | 55,9±15,8               |        |
| Degree   | Sibling                    | 23/25,3 | 58,7±19,1 <sup>a</sup>  | 0,007  | 51,1±17,8               | 0,306  |
|  | Parent                     | 25/27,5 | 77,2±21,5 <sup>b</sup>  |        | 59,6±12,3               |        |
|  | Relative                   | 14/15,4 | 64,3±5,6 <sup>ab</sup>  |        | 59,7±9,1                |        |
|  | Child                      | 14/15,4 | 61,4±15,9 <sup>ab</sup> |        | 56,4±9,9                |        |
|  | Spouse                     | 15/16,5 | 62,1±19,1 <sup>ab</sup> |        | 55,1±20,2               |        |
| Outpatient application to psychiatry service during the pandemic | 1-3 applications           | 60/65,9 | 62,5±16,5               | 0,049  | 54,2±14,0               | 0,062  |
|  | 4 and more applications    | 31/34,1 | 71,7±22,4               |        | 60,3±15,6               |        |
| Inpatient application to psychiatry service during the pandemic  | No application             | 45/19,5 | 54,6±12,8 <sup>a</sup>  | <0,001 | 49,5±14,1 <sup>a</sup>  | <0,001 |
|  | 1 application              | 35/38,5 | 75,7±17,4 <sup>b</sup>  |        | 62,8±11,6 <sup>b</sup>  |        |
|  | 2 applications             | 11/12,1 | 78,9±20,9 <sup>b</sup>  |        | 62,9±15,2 <sup>b</sup>  |        |
| Type of psychiatric medication use                               | Oral                       | 66/72,5 | 68,7±19,0               | 0,054  | 58,7±14,3 <sup>a</sup>  | 0,024  |
|  | Injection                  | 14/15,4 | 58,6±19,3               |        | 47,7±15,8 <sup>b</sup>  |        |
|  | Oral+injection             | 11/12,1 | 56,4±14,8               |        | 52,2±12,4 <sup>ab</sup> |        |
| Status of going to CMHC before the pandemic                      | Yes                        | 33/36,3 | 64,8±24,0               | 0,745  | 53,8±17,6               | 0,237  |
|  | No                         | 58/63,7 | 66,1±15,9               |        | 57,6±12,9               |        |

Note: Values in bold denote statistical significance at the  $p < 0.05$  level.  
 WHOQOL-BREF-TR=World Health Organization Quality of Life Form  
 PFBS=Perceived family burden scale  
 ZBS=Zarit Caregiver Burden Scale

**Table 2.** Comparison of the WHOQOL scale by various parameters

|  |                            | General health status |              | Physical health       |                  | Psychological          |              | Social relations      |              | Kith and Kin           |                  |
|--|----------------------------|-----------------------|--------------|-----------------------|------------------|------------------------|--------------|-----------------------|--------------|------------------------|------------------|
|  |                            | Mean±SD               | p            | Mean±SD               | p                | Mean±SD                | p            | Mean±SD               | p            | Mean±SD                | p                |
| Gender   | Female                     | 5,7±1,4               | <b>0,012</b> | 20,5±4,6              | 0,096            | 16,4±3,5               | <b>0,03</b>  | 7,8±2,1               | <b>0,006</b> | 25,5±6,2               | 0,173            |
|  | Male                       | 6,4±1,5               |              | 22,1±4                |                  | 18,0±3,3               |              | 9,0±2                 |              | 27,2±5,1               |                  |
| Marital status   | Single                     | 5,7±1,6               | 0,319        | 19,0±3,2              | <b>0,049</b>     | 16,6±2,7               | 0,543        | 8,2±2,2               | 0,678        | 22,5±5,2               | <b>0,015</b>     |
|  | Married                    | 6,1±1,4               |              | 21,6±4,4              |                  | 17,3±3,6               |              | 8,4±2,1               |              | 26,9±5,6               |                  |
| Education  | Secondary school and below | 5,6±1,2               | <b>0,005</b> | 20,5±4,6              | <b>0,024</b>     | 16,5±3,4               | 0,094        | 7,8±2,1               | <b>0,014</b> | 23,1±5                 | <b>&lt;0,001</b> |
|  | High school and above      | 6,4±1,6               |              | 22,0±4,1              |                  | 17,8±3,5               |              | 8,9±2                 |              | 28,9±4,9               |                  |
| Residence  | District                   | 6,4±1,4               | 0,166        | 22,6±4,8              | 0,326            | 17,3±4,1               | 0,842        | 8,2±2,3               | 0,870        | 25,5±4,9               | 0,316            |
|  | City                       | 5,9±1,5               |              | 20,8±4,1              |                  | 17,2±3,3               |              | 8,5±2,1               |              | 26,6±6                 |                  |
| Income   | Low                        | 5,8±1,6               | 0,684        | 21,0±5,5              | 0,636            | 16,3±4,9               | 0,784        | 7,3±2,8               | 0,183        | 22,8±4,7 <sup>a</sup>  | <b>0,034</b>     |
|  | Medium                     | 6,1±1,4               |              | 21,3±4,1              |                  | 17,4±3,1               |              | 8,6±1,9               |              | 27,2±5,6 <sup>b</sup>  |                  |
|  | High                       | 6,0±1,9               |              | 21,4±4,7              |                  | 17,4±4,3               |              | 8,5±2,1               |              | 25,2±6,1 <sup>ab</sup> |                  |
| Job  | Student                    | 6,0±1                 | 0,211        | 21,3±1,2              | <b>0,024</b>     | 17,3±3,2               | 0,127        | 8,3±2,3               | <b>0,03</b>  | 22,3±5,1               | <b>0,016</b>     |
|  | Public officer             | 6,4±1,2               |              | 21,9±3,8              |                  | 18,0±2,7               |              | 8,6±1,7               |              | 27,6±5,8               |                  |
|  | Worker                     | 5,9±1,7               |              | 20,7±4,9              |                  | 16,9±3,9               |              | 8,5±2,2               |              | 27,2±5,9               |                  |
|  | Private sector             | 6,5±1,5               |              | 23,5±3,3              |                  | 18,4±3,6               |              | 9,6±1,8               |              | 28,1±4,5               |                  |
|  | Unemployed                 | 5,5±1,3               |              | 19,6±4,8              |                  | 15,7±3,6               |              | 7,3±2,2               |              | 23,0±4,9               |                  |
| Diagnosis  | Schizophrenia              | 6,0±1,5               | 0,595        | 21,1±4,6              | 0,580            | 17,2±3,7               | 0,374        | 8,3±2,2               | 0,607        | 26,4±5,9               | 0,639            |
|  | Delusional disorder        | 6,5±1,2               |              | 21,9±2,6              |                  | 17,9±2,3               |              | 9,0±1,8               |              | 25,2±4,3               |                  |
|  | Schizoaffective disorder   | 5,8±1,4               |              | 22,0±4,3              |                  | 16,4±3,6               |              | 8,2±2,1               |              | 27,0±6,1               |                  |
| Degree   | Sibling                    | 6,7±1,4               | 0,071        | 22,9±4,3              | <b>0,033</b>     | 17,7±4                 | 0,266        | 9,1±2,2               | 0,384        | 28,3±4,6               | <b>0,011</b>     |
|  | Parent                     | 5,5±1,5               |              | 18,8±4,2              |                  | 16,2±2,9               |              | 8,0±2,1               |              | 23,0±5,5               |                  |
|  | Relative                   | 6,2±1,3               |              | 23,0±3,7              |                  | 17,7±2,4               |              | 8,8±1,8               |              | 28,3±5                 |                  |
|  | Child                      | 5,9±1                 |              | 21,3±2,5              |                  | 17,2±2,5               |              | 8,2±1,7               |              | 27,8±6,4               |                  |
|  | Spouse                     | 5,9±1,8               |              | 21,4±5,1              |                  | 17,7±5,1               |              | 7,9±2,6               |              | 25,6±5,5               |                  |
| Outpatient application to psychiatry service in the pandemic | 1-3 applications           | 6,0±1,5               | 0,827        | 22,0±4,2              | <b>0,039</b>     | 17,3±3,5               | 0,474        | 8,4±2,1               | 0,540        | 26,7±5,4               | 0,356            |
|  | 4 and more applications    | 6,0±1,4               |              | 19,9±4,3              |                  | 17,0±3,5               |              | 8,3±2,2               |              | 25,5±6,2               |                  |
| Inpatient application to psychiatry service in the pandemic  | No                         | 6,6±1,3 <sup>a</sup>  | <b>0,003</b> | 23,1±4,5 <sup>a</sup> | <b>&lt;0,001</b> | 18,2±3,8 <sup>a</sup>  | <b>0,007</b> | 8,9±2,3 <sup>a</sup>  | <b>0,004</b> | 28,2±4,8 <sup>a</sup>  | <b>0,005</b>     |
|  | 1                          | 5,5±1,3 <sup>b</sup>  |              | 19,8±3,1 <sup>b</sup> |                  | 16,7±2,7 <sup>ab</sup> |              | 8,2±1,8 <sup>ab</sup> |              | 25,1±6,1 <sup>b</sup>  |                  |
|  | 2                          | 5,6±1,8 <sup>ab</sup> |              | 18,5±4,4 <sup>b</sup> |                  | 14,7±3,2 <sup>b</sup>  |              | 6,9±1,5 <sup>b</sup>  |              | 22,6±5,3 <sup>b</sup>  |                  |
| Type of psychiatric drug use                                 | Oral                       | 5,9±1,5               | <b>0,032</b> | 20,8±4,3              | 0,228            | 16,7±3,5               | 0,102        | 8,1±2,2               | <b>0,022</b> | 25,8±5,9               | 0,175            |
|  | Injection                  | 7,0±1,4               |              | 23,1±5,2              |                  | 18,8±3,6               |              | 9,8±1,8               |              | 28,9±4,8               |                  |
|  | Oral+ injection            | 5,8±1                 |              | 22,0±2,8              |                  | 18,3±2,5               |              | 8,5±1,6               |              | 26,4±5,2               |                  |
| Status of going to CMHC before the pandemic                  | Yes                        | 6,5±1,3               | 0,064        | 21,6±5,1              | 0,937            | 17,8±3,5               | 0,325        | 8,8±2,2               | 0,271        | 26,2±5,9               | 0,785            |
|  | No                         | 5,8±1,5               |              | 21,1±3,9              |                  | 16,9±3,5               |              | 8,2±2,1               |              | 26,4±5,7               |                  |

Note: Values in bold denote statistical significance at the p < 0.05 level. WHOQOL-BREF-TR=World Health Organization Quality of Life Form. PFBS=Perceived family burden scale. ZBS=Zarit Caregiver Burden Scale

**Table 3.** Correlation analysis

|                          |   | Age          | Duration of patient care | PFBS         | ZCBS         | General health | Physical health | Psychological | Social relations |
|--------------------------|---|--------------|--------------------------|--------------|--------------|----------------|-----------------|---------------|------------------|
| Duration of patient care | r | ,613         |                          |              |              |                |                 |               |                  |
|                          | p | <b>,000</b>  |                          |              |              |                |                 |               |                  |
| PFBS                     | r | ,120         | ,128                     |              |              |                |                 |               |                  |
|                          | p | ,257         | ,229                     |              |              |                |                 |               |                  |
| ZCBS                     | r | ,082         | ,089                     | <b>,763</b>  |              |                |                 |               |                  |
|                          | p | ,438         | ,404                     | <b>,000</b>  |              |                |                 |               |                  |
| General health           | r | <b>-,264</b> | <b>-,316</b>             | <b>-,582</b> | <b>-,571</b> |                |                 |               |                  |
|                          | p | <b>,011</b>  | <b>,002</b>              | <b>,000</b>  | <b>,000</b>  |                |                 |               |                  |
| Physical health          | r | <b>-,275</b> | <b>-,287</b>             | <b>-,642</b> | <b>-,652</b> | <b>,613</b>    |                 |               |                  |
|                          | p | <b>,008</b>  | <b>,006</b>              | <b>,000</b>  | <b>,000</b>  | <b>,000</b>    |                 |               |                  |
| Psychological            | r | -,159        | <b>-,253</b>             | <b>-,650</b> | <b>-,626</b> | <b>,529</b>    | <b>,521</b>     |               |                  |
|                          | p | ,133         | <b>,016</b>              | <b>,000</b>  | <b>,000</b>  | <b>,000</b>    | <b>,000</b>     |               |                  |
| Social relations         | r | -,116        | <b>-,324</b>             | <b>-,607</b> | <b>-,590</b> | <b>,560</b>    | <b>,608</b>     | <b>,640</b>   |                  |
|                          | p | ,272         | <b>,002</b>              | <b>,000</b>  | <b>,000</b>  | <b>,000</b>    | <b>,000</b>     | <b>,000</b>   |                  |
| Kith and Kin             | r | -,166        | -,158                    | <b>-,576</b> | <b>-,480</b> | <b>,506</b>    | <b>,602</b>     | <b>,454</b>   | <b>,600</b>      |
|                          | p | ,116         | ,136                     | <b>,000</b>  | <b>,000</b>  | <b>,000</b>    | <b>,000</b>     | <b>,000</b>   | <b>,000</b>      |

Note: Values in bold denote statistical significance at the p < 0.05 level. WHOQOL-BREF-TR=World Health Organization Quality of Life Form. PFBS=Perceived family burden scale. ZBS=Zarit Caregiver Burden Scale

sub-scale scores ( $p < 0.05$ ). A significant difference was found between using psychiatric drugs in terms of health status ( $p=0.032$ ) and social relationships ( $p=0.022$ ) score. It was seen that this difference was related only to the difference between oral and injection treatment (Table 2).

A significant negative correlation was found between the duration of patient care and the general health, physical health, psychological and social relations sub-scales. A significant positive correlation was found between the PFBS score and the ZBS score, and a negative significant relationship between the PFBS score and the WHOQOL-BREF-TR scale sub-scales. A significant negative correlation was found between the ZBS score and the WHOQOL-BREF-TR scale sub-scales. It was observed that there was a positive significant relationship between the sub-scales of the WHOQOL-BREF-TR scale with each other (Table 3).

## Discussion

In this study, we found that during the COVID-19 epidemic period, the perceived family burden and care burden increased in people caring for psychosis patients, and therefore, the quality of life of caregivers was negatively affected.

The ZBS mean score of the participants was  $56.2 \pm 14.8$ . We found that the ZBS score for the female gender was significantly higher than the male score, and the general health status, psychological and social relations sub-scales, which are among the sub-parameters of the quality of life scale, were significantly higher than the scores of the women. This shows that the gender of the caregiver affects the caregiver burden. The fact that women have other occupations in home life may explain this. In addition, unlike other studies, we could not find a significant difference between education level and caregiving burden [16].

The scores of the quality of life sub-scales of the participants were reviewed. General health status average was  $6 \pm 1.5$ , physical health sub-scale average was  $21.3 \pm 4.4$ , psychological sub-scale average was  $17.2 \pm 3.5$ , social relations sub-scale average was  $8.4 \pm 2.1$  and environment sub-scale average was  $26.3 \pm 5.7$ . In our study, it was observed that the good educational status of the caregiver increased the scores of the general health status, physical health, environment and social sub-dimensions in the quality of life scale, which supports the literature [16]. As the education level of the caregiver increases, they learn more about psychotic disorder and treatment options. Thus, early interventions will be provided during exacerbation of psychosis during a pandemic process, and the quality of life of the patient and their relatives will increase.

As Czuchta et al., we observed that as the education level of caregivers increased, their quality of life increased [17]. As the education level increases, the caregiver becomes more informed about psychotic disorder and treatment options. This may have provided early interventions during exacerbation of psychosis during a pandemic period, thus increasing the quality of life of the patient and caregiver.

In the study conducted by Lasebikan et al., most of the participants were single, whereas in our study, there were fewer single caregivers [18]. We found that the family burden perceived by single people when caring for psychosis patients

was higher than that of married people. In terms of the quality of life of married people, we found that physical health and environment sub-scale scores were significantly higher than the scores of singles.

In our study, due to the difference between siblings and parents, a significant difference was observed between the degree of relationship with the patient and the perceived family burden. Again, a significant difference was found in terms of physical health and environmental sub-scale in the scoring of the quality of life scale in terms of the caregiver being siblings and parents. This supports the finding of Roper et al. in 2014 that the relationship between the siblings of mentally disabled individuals was better. However, in the study, it was stated that the family burden perceived by mothers was higher than that of fathers among caregivers [19]. In our study, we classified caregivers as parents, not separating them as parents.

PFBS scores were found to be significantly higher in the caregivers of the patients who admitted to psychiatry more frequently during the pandemic than those who admitted to psychiatry less frequently. Again, a significant difference was observed in terms of perceived family burden and caregiving burden scale scores with inpatient admissions to psychiatry. During the pandemic period, a significant difference was found between inpatient admissions to psychiatry in terms of WHOQOL-BREF-TR scale sub-scale scores. This shows that as the hospitalization of the patient increases during the pandemic period, the quality of life of the caregiver decreases. It is known that during the COVID-19 pandemic, psychiatric illnesses are negatively affected by the difficulty in drug procurement, lack of mental health specialists, lack of transportation, quarantine periods, and some of the patients themselves stop using drugs [20]. The applications to psychiatry support this situation as it shows that the patient is not in remission.

During the pandemic period, a significant difference was observed between the ZBS scale scores of the patients who used only oral medication in the treatment of psychotic disorder and the patients who used drugs as a long-acting depot injection (Table 1). It is known that the use of long-acting depot drugs is more effective than oral drug use in terms of maintaining the continuity of treatment and reducing hospitalizations, in which our findings are compatible with this situation [21]. Also, long-acting medication use has been found to increase caregiver's quality of life in terms of general health status and social relations sub-parameters.

In the correlation analysis performed, a positive relationship was found between the age of the caregiver and the duration of the patient's care. Once again, there is a significant negative correlation between age and the WHOQOL-BREF-TR general health and physical health sub-scale score. In similar studies conducted with caregivers of chronic patients, it has been found that young caregivers experience more burnout and lower quality of life scores than elderly caregivers [22]. This shows that as the caregiver gets older, psychiatric illness can be accepted more easily.

Our study determined that both BFPS scores and ZBS scores negatively affected the general health, physical, psychological, social and environmental sub-scores of the WHOQOL-BREF-TR form. Zeng et al. (2016) reported that the caregiving burden

negatively affected the quality of life in their study with caregivers of patients with psychiatric disorders [23]. Once again, Zauszniewski showed that the perceived family burden reduces the quality of life [24]. This shows that the needs of caregivers in areas such as health, social, economic and accommodation should be met during the pandemic period. We think that the perceived family burden and caregiving burden will decrease and the quality of life will increase.

Living with the psychiatric symptoms of a psychosis patient, providing care, supporting financially and spiritually affects the caregivers psychologically and physically. A meta-analysis study showed that early detection of caregiver problems is beneficial for psychotic patients in the long term. It is known that during a pandemic, many people are affected mentally negatively, and the number of psychiatric diseases increase [25]. This shows that in the COVID-19 pandemic, caregivers need more support. For these reasons, it should be ensured that the problems of the caregiver as well as the patient with psychosis are solved. Social workers working in the psychiatric field should continue to communicate with both the caregivers and the patient during the pandemic period, and contact the relevant institutions to provide the necessary support to these people. In addition, psychiatric examinations of the patients should not be neglected during this period, and if necessary, interviews should be made online. In this way, we believe that the necessary support can be given both to the patient with psychosis and the caregiver. The fact that the sample of our study consisted of 91 caregivers was an important limitation. A larger sample may yield more generalizable results. Another limitation of the study was that only the caregivers of the patients who admitted to the psychiatry outpatient clinic were recruited. However, we know that applications to psychiatry polyclinics have decreased considerably due to the pandemic. Also, when planning the study, no control group was formed. It is thought that performing analysis by including the control group in similar studies to be conducted will contribute to the literature.

As a result, this study is important in terms of examining the perceived family burden, caregiving burden and factors affecting the quality of life of caregivers of patients with psychosis during the COVID-19 pandemic. It should be kept in mind that negative situations that may arise if the caregiver is not supported may lead to greater health, social and economic problems.

#### Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

#### Animal and human rights statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

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#### Conflict of interest

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